



**Representative Louise M. Slaughter**  
**Chairwoman, House Committee on Rules**  
**Representing New York's 28<sup>th</sup> District**

# **PRESS RELEASE**

FOR IMMEDIATE RELEASE

Wednesday, March 5, 2008

The Genetic Information Nondiscrimination Act      Included as Part of the Paul Wellstone Mental Health and Addiction Equity Act      of 2007

**Washington, DC** - Rep. Louise M. Slaughter (D-NY-28), Chairwoman of the House Committee on Rules, today applauded passage of H.R. 1424, the Paul Wellstone Mental Health and Addiction Equity Act of      2007 by the House of Representatives, which included the Genetic      Information Nondiscrimination Act as a part of the bill. The legislation, known as GINA and      authored by Rep. Slaughter, was first introduced by the Congresswoman thirteen years ago.

The momentum to pass GINA comes after over a decade of fighting for federal legislation to protect Americans from genetic discrimination. It is designed to keep pace with the      rapid advancement of scientific research by prohibiting improper use of      genetic information.

**“The field of genetics holds tremendous potential for finding      cures to some of our most deadly genetic-based diseases,”**      said Rep.      Slaughter. **“By prohibiting the      improper use of genetic information, GINA encourages individuals to seek early treatment for      genetic-based diseases and participate in the studies needed for the future medical breakthroughs      of the twenty-first century.”**      The      enactment of      this bill      will dramatically      reduce the cost of health care, at      the same time allowing for significant advances in scientific and      medical      research.”

GINA was included as part of the Paul Wellstone Mental Health and Addiction      Equity Act of 2007 (H.R. 1424), a bill that permanently      reauthorizes and expands the Mental Health Parity Act of 1996 to provide      for equity in the coverage of mental health and substance-related disorders      compared to medical and surgical disorders.      This bill was sponsored by Congressman Patrick Kennedy and was      passed by a vote of 268-148.

**“Given that most mental health      diseases are genetically linked, GINA is a natural addition to Congressman      Patrick Kennedy’s bill ensuring equity in the coverage of mental health      disorders compared to medical and surgical disorders,”**      concluded Rep. Slaughter.

## BACKGROUND

H.R. 493, the Genetic Information Nondiscrimination Act, or GINA, is a bipartisan bill co-sponsored by 224 Members of Congress. The legislation was introduced in the House by Rep. Slaughter, Rep. Judy Biggert (R-IL-13), Rep. Anna Eshoo (D-CA-14), and Rep. Greg Walden (R-OR-2) on Tuesday, January 16th, 2007. The House of Representatives originally passed the legislation by a vote of 420-3 on April 25, 2007.

GINA prohibits health insurers from canceling, denying, refusing to renew, or changing the terms or premiums of coverage based on genetic information. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement or promotion decisions.

### Historical Precedents Indicate Need for Legislation:

- In the 1970s, many African-Americans were denied jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia, despite the fact that a carrier lacked the two copies of a mutation necessary to get sick.
- In 1998, it was discovered that Lawrence Livermore Laboratories in Berkeley had for many years performed tests for syphilis, pregnancy, and sickle cell on employees without their knowledge or consent.
- In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

### Broad Public Support

In 2002, 85 percent of those surveyed by the Genetics and Public Policy Center at Johns Hopkins University did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers. By 2004, it had increased to 80 percent.

## **Broad Support Among Healthcare Professionals**

In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. 60 percent indicated they would not share the information with a colleague because of the need for privacy and fear of job discrimination. Over 200 health, medical, and scientific organizations have endorsed GINA.

## **Support in the White House and Senate**

The Senate has passed this bill unanimously in the 108th and 109th Congresses. The Bush Administration issued an official Statement of Administration Policy (SAP) each time in support of GINA. However, Senator Tom Coburn (R-OK), after supporting the legislation in 2005, has had a hold on the bill in order to block action in the Senate during the 110th Congress.

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